International 22q11.2 Foundation

Newsletter June 2026

Celebrating "22q at the Zoo—Worldwide Awareness Day"

The First 22q at the Zoo

Fifteen years ago, we had the wacky idea to invite families and healthcare providers from around the world to join a celebration at zoos and parks, playgrounds and backyards around the globe, with brown bag lunches to catered affairs, face painting and parades, lawn games and coloring, singing and dancing, all to celebrate **22q at the Zoo – Worldwide Awareness Day**.

We began on February 14, 2011, and by the time we went to the zoo on May 22, 2011, we had an astounding number of locations, **65** to be exact, participating internationally. We kicked off in Australia, thanks to Maria Kamper, and then marched our way around the globe touching so many places and so many hearts. I distinctly remember when the Italians joined in by saying, "**We don't feel alone anymore**", and when the Spanish shared a video marching into the Madrid Zoo playing drums, chanting and singing with Dr. Sixto García-Miñaúr shouting "Donna, **we did it - we went to the zoo for 22q**"! And then there were Julie and Paul Wootton in the UK, with Georgia and Archie as the supporting cast – Archie in the Max Appeal bear costume. All this before crossing the pond to start our first "Zoo Day" in Philadelphia, the place where we originally thought we would have the event. Start small they said – but why do anything small?

Donna McDonald-McGinn – 2026

The International 22q11.2 Foundation proudly thanks every family, volunteer, caregiver, healthcare professional, support organization, and 22q Centers of Excellence who helped bring 22q at the Zoo — Worldwide Awareness Day to communities around the world.

From hometown zoos to parks and gathering places big and small, your dedication continues to raise awareness, build lifelong friendships, and shine a light on 22q11.2 Differences.

Together, we are creating a stronger global 22q community — one family, one event, and one voice at a time.

Thank you for making the 16th Annual "22q at the Zoo — Worldwide Awareness Day" so meaningful and unforgettable!

If you haven't already, please send your group photos to info@22q.org along with your location and zoo name so we can celebrate and share the amazing worldwide support for the 22q community.

Thank you for helping raise awareness for 22q11.2 differences across the globe!

See you at the zoo on May 16, 2027!

Check out the zoo day photos in this newsletter and visit our social media sites for more!

In this newsletter…

Photos from 22q at the Zoo 2026

International Locations (24)

- Buenos Aires, Argentina
- Gold Coast, Australia
- Melbourne, Australia
- Perth, Australia
- Mechelen, Belgium
- Toronto, Canada
- Copenhagen, Denmark
- Givskud, Denmark
- Helsinki, Finland
- Ranua, Finland
- Cork, Ireland
- Dublin, Ireland
- Valeggio sul Mincio, Italy
- Nagano, Japan
- Madrid, Spain
- Rotterdam, Netherlands
- Subotica, Serbia
- Madrid, Spain
- Gothenburg, Sweden
- Cromer, England, UK
- Leicestershire, England, UK
- Newtownards, Northern Ireland, UK
- Gavieside, West Calder, Scotland, UK
- Kingussie, Scotland, UK

US Locations (29)

- Tucson, AZ
- Irvine, CA
- Sacramento, CA
- Boca Raton, FL
- Melbourne, FL
- Tampa Bay, FL
- Atlanta, GA
- Brookfield, IL
- Indianapolis, IN
- Mendon, MA
- Gray, ME
- St. Paul, MN
- Kansas City, MO
- St. Louis, MO
- Asheboro, NC
- Colts Neck, NJ
- West Orange, NJ
- Buffalo, NY
- Columbus, OH
- Oklahoma City, OK
- Philadelphia, PA
- Pittsburgh, PA
- Sioux Falls, SD
- Austin, TX
- Beaumont, TX
- Dallas, TX
- San Antonio, TX
- Seattle, WA
- Kingwood, WV

The photos from pages 2 to 5 were obtained from Facebook under the hashtag **#22qatthezoo** and the group "**22q at the Zoo Worldwide Awareness Day**".

Dublin, Ireland

Subotica, Serbia

Valeggio sul Mincio, Italy

Photos from 22q at the Zoo 2026 (Continued)

Philadelphia, PA, USA

Irvine, CA, USA

Rotterdam, Netherlands

Photos from 22q at the Zoo 2026 (Continued)

Melbourne, Australia

Gray, ME, USA
Just 2 but a great start!

Gold Coast, Australia

Tucson, AZ, USA
Also just 2 and hoping for more!

Gothenburg, Sweden

Cork, Ireland

Photos from 22q at the Zoo 2026 (Continued)

St. Louis, MO, USA

West Orange, NJ, USA

Minneapolis, MN, USA

Colt's Neck, NJ, USA

Buffalo, NY, USA
Went bowling for 22q!

Visit our social media sites for more photos

Recent research findings on…

Palate Surgeries in Children with 22q11.2DS

Diagnosis of 22q11.2 Deletion Syndrome is not Independently Associated with Complications Following Speech Surgery: A National Surgical Quality Improvement Program Pediatric Study.

Srinivas S, Asti L, Rachwal B, Bergus KC, Fogolin A, Kirschner RE, Bergman H.
Cleft Palate Craniofac J. 2025 Jun 12:10556656251348979. doi: 10.1177/10556656251348979.

The **velopharynx** (VP) is a valve made up of the soft palate and the throat. It controls the area between the nose and the mouth. It normally opens for breathing and closes for talking.

Velopharyngeal dysfunction (VPD) is very common in children with 22q11.2DS. In this condition, the VP cannot close when talking. The speech sounds hypernasal and may be harder to understand. Children with VPD usually need surgery to correct the problem. For more information about VPD, see the Palate Series on Health Conditions Explained.

Like other surgeries, palate surgeries may lead to complications. Doctors want to find out **if 22q11.2DS increases the risks of complications and length of hospital stay**.

Setting

- USA, from 2013 to 2020

Study Population

- Children aged 5 to 10 years who had specific types of surgeries to correct their speech
- Total # patients = 3227, including 273 (8.5%) with 22q11.2DS

Methods

- Analyzed a database of medical records
- Compared children with and without 22q11.2DS in terms of:
  1. Prolonged hospital stays (>2 days after surgery)
  2. Rates of complications (within 30 days after surgery)
     - Various infections
     - Problems with blood flow to the brain
     - Seizures
     - Heart attacks
     - Need for blood transfusion
     - Need for help in breathing
     - Re-admission to the hospital

Comparing Children with and without 22q11.2DS

- Children with 22q11.2DS on average **had more risk factors** (e.g. issues related to the heart, digestive tract, brain/nerves, airway) that can potentially cause problems during surgeries.
- Children with 22q11.2DS were classified into **higher risk groups for anesthesiology** (well-being during surgery).
- 22.7% of children with 22q11.2DS vs. 10.2% of those without the deletion stayed at the hospital more than 2 days. Children with 22q11.2DS were **2 times more likely to have a prolonged hospital stay after the surgery** than those without the deletion.
- 3.7% of children with 22q11.2DS and 3.2% of those without the deletion had complications after a surgery that corrects speech. This difference is not significant. The **22q11.2DS status did not add to the odds of having complications**.
- In children with 22q11.2DS, surgeries were more commonly performed by pediatric otolaryngologists (doctors specialized in children's ear, nose, and throat conditions) than pediatric plastic surgeons (doctors specialized in performing surgeries to restore function and appearance). There were no significant differences in the odds of having complications between surgeries performed by these two types of surgeons.

Children with 22q11.2DS who undergo surgeries to correct speech problems are more likely to stay at the hospital for longer, but they do not necessarily have a higher risk of surgery complications.

It is recommended that medical centers assess each child's individual needs instead of keeping all children with 22q11.2DS for longer hospital stays after the surgery of the palate.

Recent research findings on…

Autoantibodies and Psychosis

Autoantibodies in patients with 22q11.2 deletion syndrome and psychosis.
Starkey SY, Maurer K, Bassett A, McDonald McGinn DM, Sullivan KE.
J Allergy Clin Immunol. 2025 Oct;156(4):1103-1110. doi: 10.1016/j.jaci.2025.07.013.

Background Information

Autoantibodies

Our immune system defends our body from bacteria, viruses, cancer cells, and toxins. Antibodies bind to these invaders so our immune system can clear or inactivate them.

In rare cases, antibodies ("**autoantibodies**") bind to parts of our own body. The immune system then attacks these healthy parts by mistake. This is called **autoimmunity**.

For more info, see Autoimmune Disorders in Health Conditions Explained.

Psychosis

Psychosis is a symptom in which patients have difficulty telling apart what is real and what is not. This can include believing that someone is out to harm them when this is not the case. They may hear voices or see things that are not there. The patients' thinking may seem confused or mixed-up.

Psychiatric illnesses that include psychosis as a symptom are called **psychotic disorders**. These are treatable conditions. An example is **schizophrenia**, which develops in about 1 in 4 to 5 adults with 22q11.2DS. It is important to identify changes in thinking, emotions, behavior, and functioning in order to intervene as early as possible.

For more info, see Psychotic Disorders in Health Conditions Explained.

Studies on the general population have found an association between autoimmunity and psychosis. Both of these aspects are part of 22q11.2 deletion syndrome (22q11.2DS), and there is some evidence that they may be connected in this population as well.

Researchers want to find out whether the immune system situation is different between those with psychosis versus those without. In particular, among patients who have 22q11.2DS, do the ones who have psychosis have higher levels of autoantibodies than those who don't?

Setting

- USA and Canada

Study Population

- 27 adults with 22q11.2DS (10 with psychosis, 17 without)
- 15 adults with no 22q11.2DS and no psychosis
- 29 children and teens with 22q11.2DS (1 with psychosis, 28 without)
- 8 children and teens with no 22q11.2DS and no psychosis

Methods

- Obtained blood samples from the people in the study
- Used the University of Texas Southwestern autoantibody array to measure levels of 51 autoantibodies in the blood samples

Findings

- Both adults and children/teens with 22q11.2DS had lower levels of autoantibodies compared to those without 22q11.2DS
- Among adults with 22q11.2DS, those with psychosis had much higher autoantibody levels than those without psychosis
- 8/10 adults with psychosis and the single teen with psychosis had very high levels of antibodies against single-stranded DNA. While this finding would typically indicate the presence of autoimmune disorders, these patients did not show symptoms of autoimmunity.

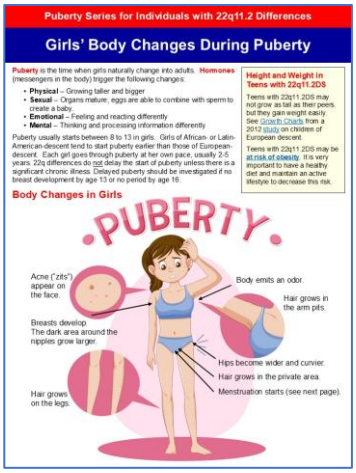
Main Message

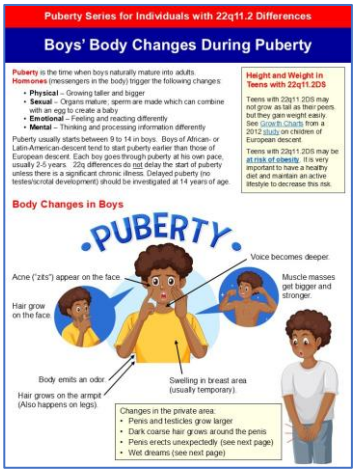
- Among patients with 22q11.2DS, the immune system in those with psychosis shows different characteristics compared to those without psychosis.
- **Patients with 22q11.2DS who also had psychosis had much higher levels of autoantibodies compared to those without psychosis.** This finding may help identify people who are at a higher risk of developing psychosis.

Puberty Series for 22q11.2 Differences

We have recently prepared 3 info sheets for the Puberty Series for 22q11.2 Differences. This newest series in Health Conditions Explained talks about body changes, behavioral challenges, and sexual health concerns that teenagers may have. We are also providing links to additional resources to help parents talk to their teens about various issues.

Many thanks to Joanne Loo, PhD, Programmatic and Educational Tool Developer and Natalie Blagowidow, MD, Obstetrician/Gynecologist for developing and reviewing the Puberty Series. We also thank Samantha D'Arcy, MHSc, RD, Registered Dietitian; Nikolai Gil D. Reyes, MD, Neurologist; and Maude Schneider, PhD, Psychologist and Psychotherapist for reviewing the specific subtopics.





Here are the 3 topics published so far.

- **Girls' Body Changes During Puberty**
- **Boys' Body Changes During Puberty**
- **Staying Clean and Healthy**

More topics will be available later this year.

Recently Published: Eye Series

- Eye issues in 22q Differences
- Introduction to the Eye
- Refractive Errors
- Reduced Vision
- Strabismus (Misalignment of the Eyes)
- Sclerocornea
- Ptosis (Droopy Eyelid)

Be sure to check out all the topics in the "**Health Conditions Explained**" section of our website!

- **Heart Series**
- **Dental Series**
- **Palate Series**
- **Eye Series**
- **Mental Health Series**
- **Speech Series**
- **Sleep Series**
- **22q Glossary (4th ed.)**
- **Gastrointestinal (GI) Series**
- **Immune System Series**
- **Brain and Nerves Series**
- **Eye Series**

Clinical Recommendations for 22q11.2DS
Endorsed by European Reference Network ITHACA

A European network for rare syndromes has endorsed the two sets of updated clinical practice recommendations for managing individuals with 22q11.2DS. Their approval means many more healthcare providers will come across these documents.

Updated clinical practice recommendations for managing **children** with 22q11.2 deletion syndrome
Óskarsdóttir S and team. Genet Med. 25(3): 100338, 2023 DOI: 10.1016/j.gim.2022.11.006

Updated clinical practice recommendations for managing **adults** with 22q11.2 deletion syndrome
Boot E, and team. Genet Med. 25(3): 100344, 2023.DOI: 10.1016/j.gim.2022.11.012.

22q11.2 deletion syndrome (22q11.2DS) is not a well-known condition. Many patients and families with 22q11.2DS meet medical providers who are unfamiliar with it. In 2023, the 22q11.2 Society published two sets of updated guidelines for to help professionals take care of children and adults with 22q11.2DS. These documents were also translated into French, Spanish, and Chinese.

The European Reference Network for Rare Malformation Syndromes, Intellectual, and Other Neurodevelopmental Disorders (ERN-ITHACA) is network of 71 expert medical centers and 45 European Patient Advocacy Groups. Their members span 26 countries (25 out of 27 countries from the European Union, plus Norway).

The members work together to share knowledge and resources to support people with rare syndromes. The network also provides education for healthcare professionals and promotes collaborative research.

In May 2026, **ERN-ITHACA endorsed the two clinical recommendations documents for 22q11.2DS**. They have now posted these documents onto their Endorsed Guidelines page, which means **many more healthcare providers will find out the best ways to manage 22q11.2DS**. This is definitely great news for patients and families with 22q11.2DS.

Clinical Recommendations for Adults Now in Dutch!

The clinical recommendations for adults with 22q11.2DS is now available in Dutch!

We thank Erik Boot, Claudia Vingerhoets, and Joanne Loo for their hard work and dedication.

Updated clinical practice recommendations for managing children with 22q11.2 deletion syndrome

- English (Original) – Endorsed by ERN-ITHACA
- French – Français
- Spanish – Español
- Simplified Chinese – 简体中文

Updated clinical practice recommendations for managing adults with 22q11.2 deletion syndrome

- English (Original) – Endorsed by ERN-ITHACA
- French – Français
- Spanish – Español
- Dutch - Nederlands **[NEW]**
- Traditional Chinese 繁體中文

Prenatal Screening and Diagnostic Considerations for 22q11.2 Microdeletions – English

Speech-Language Disorders in 22q11.2 Deletion Syndrome: Best Practices for Diagnosis and Management – English

Expert healthcare providers are currently preparing a document that will provide detailed information on features associated with the chromosome 22q11.2 duplication syndrome (22q11.2DupS). In the mean time, these experts are using the same healthcare guidelines prepared for the 22q11.2 deletion syndrome, as the associated features are quite similar, just with lower frequency. Thank you for your patience.

Meet Sadie

Originally posted on the Foundation's website on February 25, 2026.

A Heart Bigger Than the Moon – Cover of the 2026 Faces of Sunshine Calendar

Sadie turned three in March. She was born in Johnson City, New York — a tiny girl with a big presence that her family would soon discover was even bigger than they imagined.

Shortly after birth, Sadie spent time in the NICU. During that stay, doctors discovered she had a ventricular septal defect (VSD), a small hole in her heart. Her parents also noticed something unusual — when she drank milk, it often came out of her nose. At the time, there were questions but not yet answers.

At two weeks old, Sadie's newborn screening flagged her as potentially positive for Severe Combined Immunodeficiency (SCID). That result led her family to meet with an immunology team — a meeting that would change everything. While Sadie did not have SCID, she was diagnosed with 22q11.2 deletion syndrome at six weeks old. That same visit helped connect the dots: Sadie had an incompetent palate, which explained her feeding challenges.

Like many families receiving a 22q diagnosis, Sadie's parents entered a world of new terminology, appointments, and unknowns. But alongside the medical complexities came clarity — and a plan.

From early on, Sadie began receiving Speech-Language Pathology services. For the first 18 months of her life, she also participated in Physical Therapy to address torticollis and mild physical delays. With support and early intervention, Sadie has continued to grow and thrive in her own unique way.

And what a way that is.

Sadie loves firetrucks, airplanes, the moon, and Bluey. She has a curiosity about the world that lights up every room she enters. But what truly sets her apart is her heart — a heart that, despite its early challenges, is overflowing with love. She shows it constantly through her affection for her family and her friends at school.

While Sadie experiences expressive speech delays, she is a remarkable communicator. With more than 150 American Sign Language signs, she has become what her family proudly calls a "rockstar communicator." In fact, she has inspired many people around her to learn sign language so they can connect with her more fully. Her journey has not only strengthened her own voice but expanded the language of those who love her.

Her family shares an honest truth that resonates with many in the 22q community: grieving the "easy, carefree" life you once pictured is part of the process. But moving forward — day by day — opens the door to something just as beautiful. Every single day, Sadie shows her family how amazing she is. And part of what makes her who she is, is 22q.

Looking ahead, her parents hope for what all parents hope for — that Sadie will be happy, healthy, and able to pursue anything she sets her mind to. And if her first three years are any indication, there is very little that will stand in her way.

Sadie's story is a reminder that children and adults with 22q11.2 deletion syndrome are extraordinary. Sharing their stories builds awareness. Awareness builds understanding. And understanding builds acceptance.

And that makes the world better — not just for Sadie — but for everyone. 🧡

A Missing Piece

Our very own Donna McDonald-McGinn recently published an article called "22q: The Missing Piece" in Helen: The Journal of Human Exceptionality.

The article follows the journey of Louis, the son of our Foundation's Director, Carol Cavana, from childhood to adulthood. Donna also discusses the symptoms of 22q as well as the importance of early detection and coordinated multidisciplinary care.

Read the full article on: https://helenjournal.org/march-2026/22q-the-missing-piece

About the author of "The Missing Piece": Donna M. McDonald-McGinn, MS, LCGC, Founding Board Member of the International 22q11.2 Foundation, Chair of the 22q11.2 Society, Director of the 22q and You Center at the Children's Hospital of Philadelphia, and Professor of Clinical Pediatrics at the Perelman School of Medicine of the University of Pennsylvania.

2026 Lighting Request Letter Now Available

Let's raise awareness for 22q differences!

We invite you and your town to join an international movement of lighting up buildings and monuments in red on the evening of **November 22nd** (**22/11**; or 11/22 in North America) as a play on the name of the 22q11.2 deletion and duplication syndromes.

Some buildings may already have an online system for submitting lighting requests. If you do not find an online form, you can use a letter from our Foundation to **request red lighting on Saturday, November 22nd, 2026**. Click on image of the letter on the right to access the pdf file of the letter. **Download** the file to your own drive or cloud. Fill in the name of the building and the city or town, then email or mail the letter to the government or organization that manages the building.

On the night of **November 22nd, 2026**, take pictures of yourself with the illuminated building and share them on social media.

Together, we will light up the night for 22q!

Light up the Night for 22q11.2!

Greetings from the International 22q11.2 Foundation, Inc.

November is 22q11.2 Awareness Month!

22q11.2 deletion and duplication syndromes are under-recognized genetic conditions that affect about 1 in 1000 pregnancies and 1 in 2000 live births. These conditions occur when a very small piece of chromosome 22 is missing or extra, resulting in the loss or gain of about 50 genes that help direct how the body is formed and functions. The most common associated features include birth defects (such as heart, palate and kidney problems), multiple medical conditions (including low calcium, difficulty fighting infection, feeding and swallowing differences, and seizures), developmental delay, learning differences, and behavioral health problems, such as ADHD, anxiety, autism, and psychiatric illness. Many individuals require care from multiple specialists across the lifespan, but there is also very broad variability.

Most deletions and duplications are the same size with a subset being a bit smaller. All can occur randomly for the first time in the person who has the chromosome difference and nothing that the parents did or did not do cause it to occur. However, once a person has the deletion or duplication there is a 50% chance of passing it on in every pregnancy.

Chromosome 22q11.2 differences are the most common chromosomal conditions after Down Syndrome. However, most people have never heard of chromosome 22, and some people with these differences spend years searching for a diagnosis. To increase public awareness, in 2018, La Asociación Síndrome 22q11 in Spain launched an awareness campaign entitled "Luces por el 22q" (Lighting the Night for 22q). Buildings and monuments were illuminated in **red** on **November 22** (22/11 in many parts of the world but 11/22 in North America) as a play on the name of the chromosome difference. Cities in Belgium, Poland, Canada, Finland, Germany, and the USA soon followed. At the bottom of this page are example photos from November 22 of previous years, where buildings were lit up in **red** to support 22q awareness. Please consider joining this international endeavor so that no child or adult struggles to find a diagnosis in a timely fashion. Therefore, we respectfully request that _____ in _____ be lit up in **red** on **November 22, 2026** to raise awareness for **chromosome 22q11.2 deletion and duplication syndromes**. Questions? Please contact the International 22q11.2 Foundation, Inc. at 001.877.739.1849 or info@22q.org

Thank you in advance for your kind consideration.

The International 22q11.2 Foundation, Inc.
PO Box 532
Matawan, NJ 07747, USA
https://www.22q.org/

Lighting Request Letter

Donate Now

Our mission: to improve the quality of life for individuals affected by chromosome 22q11.2 differences through family and professional partnerships.

International 22q11.2 Foundation

What would we do with the funds:

- Support Research
- Support family conferences
- Support awareness
- Support Newborn Screening
- Support and raise awareness for 22q!

Your support makes a difference!

There are so many options for **Team 22q Fundraising**! Take part in one of the Foundation's event or create your own.

Please visit the **Donate** page on our website for information on donating online, by mail, or via other methods.

Please also **Shop** on our webstore.

For more information, please visit our website at **www.22q.org** or email us at **info@22q.org**.

Team 22q Fundraising

- **Tell 22 Friends** about 22q
- Become a **monthly donor**
- Be a 22q Citizen Journalist and share your event on social media!
- Plan a **22q at the Zoo** event
- Plan a **22K for 22q** event
- (It can also be 2.2K!)
- Create Your Own Event or Fundraiser Contact us at **info@22q.org**

Thank you!

Connect With Us

The mission of the **International 22q11.2 Foundation** is to improve the quality of life for individuals affected by chromosome 22q11.2 differences through family and professional partnerships.
This information is brought to you by the Foundation for educational purposes only. It is not intended to be taken as medical advice. If you have concerns, please talk to your healthcare provider.

International 22q11.2 Foundation, Inc.
PO Box 532, Matawan, NJ 07747
www.22q.org (877) 739-1849 info@22q.org